

California Institute for Regenerative Medicine Diversity Focus Group August 26, 2006

On August 26, 2006, the California Institute for Regenerative Medicine (CIRM) conducted the second of two focus group meetings that were part of the data collection process for the creation of its Draft Scientific Strategic Plan. This meeting was structured around questions regarding the focus, goals, and values of CIRM, among other issues, as seen through the lens of diversity; the discussion in response to those questions is summarized below. This summary is not intended to be comprehensive with respect to reporting the discussion, nor does inclusion in this summary imply any commitment or endorsement by the CIRM.

INTRODUCTIONS

- ➤ Zach Hall welcomed the attendees and thanked them all for participating in the discussion. He stressed that as one of CIRM's values, diversity was important to the success of the Institute. He added that the goal for today's discussion was to address diversity as it relates to CIRM as a state granting agency and as it relates to stem cell research in general.
- ➤ Dr. Hall also acknowledged the efforts of Pam Fobbs, Chair of CIRM's Diversity Advisory Group, and Gil Sambrano, CIRM's Scientific Review Officer, for their efforts in putting together the focus meeting.
- > Pam Fobbs and Gil Sambrano discussed the format for the meeting.
 - There will be a number of areas that will be covered with respect to diversity, including diversity of biological materials, scientists, and contracts.
 - All participants received a one-page sheet with one proposed definition of diversity as a way to try to put the discussion into context.
 - A set of questions was developed to guide the discussion and address issues of diversity such as how it relates back to CIRM in terms of being a state granting agency and how it relates to stem cell research. The discussion for each question was to be kept to about 20 minutes.

DISCUSSION QUESTIONS

- 1. In ten years how would you define success?
- ➤ Participant #16: First let me ask: what are the objectives of the Institute? What are its top goals?
- ➤ Zach Hall: We would like your input on that where we want to be in ten years. We want you to contribute to the whole plan from your particular perspective, from the point of view of diversity. We are not a research organization we are a funding agency of the state that will fund research in the state of California on stem cells and related therapies.
 - Proposition 71 was passed by a large majority of the state's voters and we have a responsibility to them. We have a responsibility to advance new areas of science and we want to do it in the best possible way.
 - We are engaged in a strategic planning process which will take 6 months. We will prepare a draft of the plan which will be presented in October.
 - We have been engaged in a large data collection effort for the last several months. We have talked to people in interviews and had a number of meetings. This is one of those meetings and today we want to address the issue of diversity
 - The ICOC has addressed a series of values to guide CIRM. Those are described in a sheet in your folder and diversity is listed as one of them.
 - We would like you to share your experiences, thoughts, and perspectives and inform us on ideas and strategies we might pursue. We look forward to a lively discussion.
- ➤ Participant #18: Ten years can just fly by. What I would define as success as it relates to stem cell research and diversity is a citizenry more informed about stem cell research. Success would be that a larger percentage of the state's multicultural population is aware of stem cell research. There are still people that don't understand what it is. We want them to be able to know about it, define it, and discuss it. That would be the first thing.
- ➤ Participant #10: I see this as a three billion dollar "garage", like the garages the computer industry was born in. I see a huge opportunity for CIRM because it gives us all the opportunity and possibility of being there in the garage. The purpose of this meeting as I see it is to look how we can make sure the garage door is open. We have tremendous appreciation for the minority doctors associated with the CMA and appreciate the efforts of the Greenlining Institute in this regard. We have a real need for articulate representatives from these various groups to get involved and make sure CIRM is addressing the right issues so we can put our arms around topics, specifically diversity issues. If we're going to get there, we need your input.
- ➤ Participant #19: It's about research and how to deliver the results. As for the direction of the research, we need to ask how to be diverse in biology, patients, etc. We also have a role to play in education outreach and community outreach, which will be essential at the beginning. How can we bring medical facts to different groups to educate them and get greater participation? We need to be aware of cultural attitudes when we educate people and increase their participation and make them more capable of doing stem cell research.

We also need to have equal advances in industry. I would like to see advances in these areas.

- ➤ Participant #13: I would like to see CIRM evolve from a funding agency and leverage the \$3 billion and become a regulatory body, so that every time there's an RFA, grantees have to demonstrate diversity in their suppliers and researchers and plans for developing research that is accessible across all ethnic lines in California before applying for a grant. This is where CIRM has the most leverage in terms of impacting diversity.
- ➤ Participant #1: At the end of ten years, there should be at least one successful stem cell intervention. Then we can parse out the role of ethnicities that is the next question. But unless we have an outcome, the rest is process, and it's a disappointment. With this kind of talent, we need at least one advance that has a major impact on the population.
- ➤ Participant #16: There is an evaluative piece and that needs to be strong to look at effectiveness. We are talking about stem cell research in the US; I would hope we'd make progress internationally as well. The evaluative piece is outcomes how we determine what success is. This has to do with not only looking at specific diseases but specific diseases in specific populations including vulnerable populations. It's not just about ethno-cultural populations, but looking at children and adolescents. We need to look at those populations who could benefit from whatever the outcome is. We have to look at the developmental aspects too. Let's be clear about the evaluative piece in how far we can go and what are the limitations and future endeavors.
- ➤ Participant #1: That's a wonderful contribution, because diversity is more than thinking about ethnicities. Success needs to be evaluated and there should be points of evaluation. We also need to ask how do we measure success and how do we choose projects to fund?
- ➤ Participant #11: In about ten years, I think the stem cell field and industry should be almost where the biotech industry is today, that is, having a number of therapies out on the market. Because we're doing all this advanced planning, the industry and research fields won't have made the mistake of ignoring diversity with respect to responses to therapies. We won't be playing catch up or pulling items off the market like the pharma industry. We also won't make the same mistakes as were made with genetically modified foods. We need to make sure the public is constantly with us and we're addressing the issues and people's concerns.
- **Zach Hall:** It's important to remember that the biotech industry is 25 30 years old.
- > Participant #11: The genome project progressed at an ever accelerating rate we can do a lot in ten years.
- ➤ Participant #8: There are two parts to my answer. Success is having some sort of concrete scientific and clinical achievements. The other is to have created a new or evolved model for a public institute in terms of transparency and innovation in research funding and types of grants awarded and active participation by citizens. With respect to becoming a regulatory agency as was suggested earlier, we know the ICOC takes that role

seriously. Technically, they can only regulate its grantees, but the Standards Working Group sees the regulations and the models hopefully as models for more general regulations the state will adopt for other state funded research. We hope these will be seen as good models for people doing research in other areas.

- ➤ Participant #5: We want healthier people and a healthier world. Finding a cure should be a goal, but the process itself creates a healthier community. We need to look at key indicators that can help create a healthier community. We're looking for cures to cure all people, so we should be thinking about how the process could lead to healthier communities and what those key indicators can be.
- ➤ Participant #10: As far as being a regulatory agency, I hope the organization will be much stronger than the need to be a regulatory agency. If we built the mechanism now, in ten years the Institute will be set in terms of understanding diversity in research and the economic opportunity will be there. If we have to make a regulatory industry in ten years, then CIRM hasn't quite fulfilled its purpose. This should be set out in the beginning rather than CIRM conforming to a bureaucratic model in ten years.
- ➤ Participant #13: That's exactly what I was envisioning when I made the suggestion. CIRM should be collecting data and have policies in place that ensure diversity is a key principle and that grantees demonstrate that from the beginning. It's not a regulatory process, but right from outset, we need to set up regulations that will govern all aspects of the grant making process in a way similar to the regulations that have been set up so far, which are set up well. We need to make sure we keep at it and don't let grantees who are all talk but who are not making progress with respect to diversity get CIRM grants.
- ➤ Participant #6: Perhaps instead of funding grants 100% at the front side, CIRM could do a 75/25 where it provides 75% of the funding based on expectations of the grantee but withholds the other 25% until after 75% of the work is completed to check and see if grantees are following the guidelines with respect to diversity. If you put in a safety net requirements at the beginning, it would take care of itself.
- ➤ **Participant #5:** I want to stress the value of accountability and CIRM's role in holding grantees accountable. I think CIRM can hold grantees accountable to many principles.
- **Zach Hall:** Accountability is one of our values
- ➤ Participant #12: CIRM has to be careful that what is funded is germane to diversity issues and impacts those populations. The emphasis isn't just on diversity of research staff but the issues that are going to impact those communities.
- ➤ Participant #10: Through joint ventures with other organizations or governments, CIRM can provide a real strength. CIRM might not be able to regulate other countries, or even its own country, but it can put together a set of criteria or a "bully pulpit" for these other organizations, internationally or within the US, as to whether we are going to work with them or not.

- ➤ Participant #1: CIRM can be a model. It's important for us to understand that as a model, CIRM then becomes something that others can see and really represents an ability to take all the state's populations into consideration. The idea of some sort of trigger to make sure that happens before fulfillment of the rest of the grant is a good idea and a great opportunity for CIRM to become that model.
- ➤ Participant #16: That monitoring piece should also ensure the mission and goals of CIRM continue. But I want to back up. I want us to be careful about diversity in terms of how we define it. The term "diversity" can be used loosely and get lost, so we need to take a look at how we define and measure diversity. I think we all need to be clear about diversity and what we mean by it. Sometimes it is so broad it is not addressing those populations that the initial mission is established for. In ten years we need to take a look at how we define and measure it. We need to keep our working definition in mind.
- ➤ **Gil Sambrano:** We put a definition up front, which came from the time I was at UCSF. The Chancellor's committee put it together at that time. We need to think about what we are referring to when we say "diversity" and keep in mind other aspects of diversity as they come up, such as children, seniors, etc.
- ➤ Participant #2: One point made earlier is a great one: CIRM is about possibilities and the exploration of new territory. In my experience, regulatory agencies don't do what CIRM is trying to do; they provide constrictions and restrictions and we're trying to provide possibilities. We do need regulations to explore new territories, but I'm not sure how this institute can become regulatory in nature. I believe stem cell research has broad relevance for a broad range of diseases. Over the course of the next ten years, given my experience with the regulatory process for drug development, it may not be realistic to say we'll have products on the market but we will have proven the therapeutic concept on several disorders. Much of that potential and the attraction of this field are its broad relevance and potential. At the end of the day, CIRM is a granting agency and I would like to see it become the gold standard for what a granting agency does, and that includes diversity as one aspect and giving grants to people who make advances in human health and that pioneer advances that ultimately make a difference for patients.
- Participant #16: We need to focus on diversity for the purpose of conducting research. If you are aware of the FDA guidelines to review new drug entities, you know there are guidelines that state that if a disease has a high prevalence in a certain population, the FDA expects that a significant percentage of patients representing that population are in the clinical trials along every step of the way. These guidelines are not being enforced yet, but will be more so in the future. Although they are not enforced, several products have been delayed in approval because they did not have sufficient numbers of patients from these populations. When we define diversity for patients in terms of ethnicities we also need to include diversity of investigators in terms of ethnicities. We still have drugs sent to the FDA in diabetes and stroke that don't represent the percentage of the populations afflicted with the diseases. CIRM needs to ensure diversity in clinical trials and the investigator mix and the scientists who are in the discovery process; before getting to proof of principle we should think if terms of narrowing the definition.

- ➤ **Pam Fobbs:** What have the barriers been in the past to having people of diverse ethnic backgrounds participate in clinical trials?
- ➤ Participant #16: It's primarily in terms of perception. Some populations don't trust the system and don't trust that things are being done for their benefit. This goes all the way back to the Tuskegee experiments.
 - If people are educated they will see the benefits to themselves. If there are more diverse investigators involved in clinical trials, you will get more diverse patients in trials. Also, research institutions, private or otherwise, have to have a strategic initiatives or objectives to make sure we get diverse populations into trials.
 - I told my own industry that if we want diversity in trials we need to get clinical research organized to get that diversity. A Contract Research Organizations (CRO) with timelines to deliver 30 trials with no requirements for diversity will go to investigators with whom they have worked the most with in the past; these investigators are predominantly white. We should require CROs who recruit patients into trials to get the diversity in the trials and demand that they won't get payments if they don't. There needs to be incentives. A CRO that has no requirements for diversity will go to the investigators with whom they have the most experience, who have patients who are predominantly white, and they will tap into that patient population.
 - There are lots of dynamics working and we need to do things differently than in the past. Part of that is the education of large groups of consumers about the value of clinical trials and how they can be involved. They're not being marketed to and sought after.
- ➤ Participant #12: I agree. There are not many African American or other minority clinical researchers who are trained and well versed in clinical trials, which will impact the number of ethnic patients you can get. There's also a perception that it's more expensive and troublesome to enroll ethnic subjects in clinical trials because of socioeconomic barriers. Also, in terms of where you want to be in ten years, there's got to be a political component so that you're viewed in a more favorable manner by not only your patients but also your legislature.
- ➤ Participant #10: These private CROs should also be engaged because the private companies use the CRO's research contacts and they control the enrollment. If you have no contacts in the minority community, you won't enroll big blocks of minority patients. I'm not sure it's the same in Universities they have some type of outreach. Private organizations should look at some ways to enhance minority enrollment.
- ➤ Participant #16: The NIH has a diversity requirement of investigators and they have always been able to reach the goals of diversity in their trials because they are required to. Maybe we should get a copy of that requirement and determine how to use it as a guideline.
- ➤ Participant #3: Looking at clinical research in pharma, an investigator is allowed to go out and recruit using monetary deals. Is it possible we can do the same with stem cell

donors? The only way we can make sure we can register patients of diverse backgrounds is to make sure we have the monetary means to incent them to participate.

- Participant #16: There are two other vehicles. The National Medical Association can take on major initiatives to investigate this and be involved in a more aggressive process of outreach and education. As more of that happens and more opportunities are opened up for investigators to be involved, there may be is a willingness to include inexperienced investigators as long as they've been certified. If they have infrastructure and capacity, you won't have to go out and do as much paying to get patients. We also need communication strategies for a diverse population. We're going to have a little more difficulty with stem cell research because it's not yet a major area of research in the scientific environment. You have the challenges of being the first. On one hand, we have the challenge of making sure we include diverse populations in our research, but on the other hand, it may not be as difficult because everyone is starting at the same level.
- ➤ Zach Hall: We have to remember we are talking about a biological reagent that has its own set of genes. One of the issues we will face, long before we get to clinical trials, is how can we be assured that there are lines in place that reflect the genetic diversity of the population? As long as we depend on fertility clinics, we are looking at a population of stem cells, as someone once said, that is rich, white, and infertile. We can begin the discussion with the technical point that there are potentially alternative methods of generating stem cells. These methods, though not yet successfully demonstrated with human cells, would allow you to take a cell from any adult and put it into a stem cell line. This is a very powerful tool in terms of having cell lines for the diseases that affect minority populations and having cells that are available for use by minority populations. This has large implications on the diversity of the population we are able to serve.

2. What you believe to be one of the most significant issues in regards to diversity?

- ➤ **Arlene Chiu:** How is it that we can get cell therapies and a diverse representation of lines created to generate such therapies? Let's start there.
- ➤ Bob Klein: I'd like to join applicability to community outreach and education. A statement was made that there is a lack of trust. One of the first areas of robust possibility is the use of cord blood cells for people with sickle cell anemia, and I reference Dr. Lubin's work at Children's Hospital of Oakland. Cord blood transplantation has been shown to be effective in treatment of sickle cell anemia but there is a mortality and / or morbidity risk. Unless we do outreach to show that these people have been counseled and educated and had access to scientific information to preserve their lives, and with newspapers loving to play up the negative, we're going to prejudice the minority population, in the first area of stem cell research they see which might have potential application to them, against participation. We have an immediate need to get out there with information about the character of the risk these people are taking to preserve their lives. Since we may issue grants in all these fields we have a responsibility to recognize this is a major risk for us and a major responsibility to seize the opportunity for education before we fall behind because of negative press.
- **Zach Hall:** There is a scientific issue that impacts our ability to study disease in diverse populations and that is our ability to create lines that reflect the genetic diversity of those

populations, which depends on a technology called nuclear transfer or therapeutic cloning. The religious right has tried to confuse therapeutic and reproductive cloning, which as been banned by a number of states. To create a *therapeutic* clone, you take an unfertilized egg, take out its nucleus, and put in a nucleus from any adult cell in a process formally known as somatic cell nuclear transfer (SCNT) and more commonly known as therapeutic cloning. This allows us to create diverse stem cell lines with varied genetic constitutions. It needs to be understood that therapeutic cloning gives us disease models of a wide segment of the population. It means we can study disease among diverse groups. If we can provide information about this for your groups, that is important. Having our constituents understand the difference between therapeutic and reproductive cloning will impact our ability to develop these diverse cell lines.

- ➤ Pam Fobbs: Where are the federal guidelines as it relates to this? It is legal in California? Can we do that research here? [Note: Therapeutic cloning is legal in California] There is attempt to stop it at the federal level; the minority population needs to know what is at stake here
- ➤ Participant #16: This really speaks to the need to educate the community in a way that it becomes subject friendly so patients understand it. Whether it's this committee or another committee there needs to be an ongoing dialogue. Hopefully, this is not the last time a group convenes to discuss this.
- **Zach Hall:** If anyone in this group would like information on this topic or would like one of us to come speak to help inform and educate the groups that you represent, we would be happy to do this. We want to keep the dialogue going not only with you, but the groups you represent as well.
- ➤ Participant #13: Education is critical if we're talking about diversity of genetic materials and getting people involved in clinical trials. There are barriers we have to overcome to make sure future therapeutics and diagnostics are available, including educating people about the difference between reproductive and therapeutic cloning. Children's Hospital of Oakland has had success in recruiting patients because its efforts at outreach and education were performed by someone who is African American. It's empowering to have community workers educating their own populations on the benefits of stem cell research to create a young and growing electorate that could vote for another CIRM in 10 years.
- ➤ Participant #12: In terms of reaching the community, you have to have credible spokespeople in that community. You need someone people will respond to, who they want to be like and trust. Patients trust their doctors, so we need to make sure minority doctors and those that treat minority patients are hooked into what's going on in stem cell research.
- > Zach Hall: We can also work through the churches and the pastors. When I was at the NIH, there was a stroke trial. Tuskegee was not that far away, so we worked through the churches and convinced the pastors and ministers to help and we were able to get high a

recruitment level and establish sense of trust. You need to know the culture to know the elements you can work through.

- ➤ Participant #10: As far as getting out to the community, one thing most institutions don't realize is the disparities between the minority media and the general media. Very little information reaches out to the minority media. If it's possible to identify a working group of reporters at community newspapers and talk with them and make the knowledge more easily understood that would be helpful. Perhaps we should extend an invitation to the minority media. CIRM should make it part of its plan and strategy to invite them in and have written documents that are understandable so they could include them in their newspapers.
- ➤ **Bob Klein**: With respect to this organization, having some of the people here join in with the communities may make the editors more receptive. With respect to SNCT, there's an important point Zach made. The ideological right has been calling the resulting cell line embryos and associating them with fetuses. Based on a psychological experiment, when people think of human embryos, they draw a picture of a baby. In Missouri, a bill to criminalize SCNT was vetoed by a republican governor. The winning argument was he was convinced this was not an embryo and the important point for him was there was no sperm involved. It's important to change this terminology, to talk about this as a blastocyst, not an embryo. An embryo is caused by fertilization with sperm, which is not involved in SCNT. This kind of terminology is very important in the political aspects and because of this, the words "embryo" and "embryonic" do not exist in Proposition 71. Rather, progenitor cells are discussed in Proposition 71. Making that scientific differentiation a political differentiation is important messaging.
- ➤ **Participant #12:** I agree that the nomenclature is important.
- ➤ Participant #18: With respect to education, developing focus groups with ministers of your "mega" churches and linking with them in a partnership to educate the community could be very successful. One way to reach the African American community is through the churches. This can help us enlighten and inform people by using the right nomenclature. It could help us get the message out in an effective way.
- ➤ Participant #19: From a different angle, if we can do public relations or short advertisements on the scientific side to break the myth that stem cell research is hurting a life, it would be helpful. We can use a scientific forum to break that myth and use different languages and media, like TV and radio, to spread our message. That can be an important catalyst.
- ➤ Participant #16: Sometimes the semantics are so convoluted you may not understand it and therefore you won't support it. Our message needs to be clear and understandable. There is a faith based initiative where the NIH is looking at RFAs with a faith based component to them. I don't know who is in charge of developing those RFAs and conducting the review but this is getting funding. This may be something you may want to consider. One key question with respect to the selection criteria is how researchers will address the challenges that are unique to certain communities as opposed to submitting a

proposal without addressing them. I would also suggest that there's not only diversity in who gets funded but in who is reviewing and making funding decisions. The peer review committee needs to be diverse and be committed to diversity because it will recommend the funding. Researchers may submit proposals that are not funded because the peer review committee doesn't value the essence of what the proposal is because it is lacking in diversity.

- ➤ **Bob Klein:** If there is a proposal that has a specific diversity value, a proposal of specific significance that is rejected, the review committee can issue a minority report and can bring it to the full board.
- ➤ Participant #1: The Asian press is always looking for information but it's better if you can tie it to an issue that's relevant to the community. Does CIRM have a PR department that's working with the ethnic minorities? You may not have the expertise right there to help get it, but the impact that can be made by working with the radio shows and news media for the Chinese community here in the Bay Area is enormous; that is much better than working through the mainstream media. In regards to cell therapies, one of the big points minorities need to understand is that if we don't participate, we won't get the diverse studies we will want. That kind of message needs to come out. As far as funding research, I have no question we should have peer review that includes minorities.
- ➤ **Bob Klein:** We have a position on the Chairman's staff that we had to cut back, but that position was able to bring in 15 patient organizations and 15 institutions filing on our behalf in the courts. We have an affirmative responsibility if we are to be successful to create gateways of communication.
- ➤ Participant #13: I agree about the need for diversity in the peer review bodies. It seems like the case with CIRM is the ICOC makes the final decision and we need to recognize that the ICOC doesn't reflect the diversity of California. We need to find better ways to address that lack of diversity, maybe by working closer with the Diversity Advisory Committee.
- ➤ Participant #10: With regards to education, if you start explaining information many people in the community aren't going to get it. Is it possible to describe the process so that you don't leave your readership behind? I mean breaking it down so that people can understand it without having to ask someone, to look at books, etc. It's got to be obvious.
- ➤ Participant #8: Don Reed put it well when he described nuclear transfer as working with an egg from which you take the half set of chromosomes, replace it with a full set from the tip of your finger or your cheek, and apply a stimulus to get it to multiply so you can then study the disease that your child has. It's not a human being but a cell you constructed so that you could find a cure for disease that affects living human beings
- ➤ Participant #16: There needs to be a multicultural and multifaceted communications plan. If CIRM develops a plan that takes all the different approaches needed to gain acceptance into account, and many of you have given examples, this may raise awareness. My question would be this: who or what committee will take on that responsibility in

developing a draft of a multicultural communication plan that would then come back to this committee for input?

- ➤ Zach Hall: We just hired a new communications officer and he will work with the Diversity Committee that Pam chairs. This is an important area for us. We will address this from a broad perspective that reflects the ideas we've heard today.
- ➤ Participant #16: I understand you have a committee but do you have anyone on your staff? Just in developing multicultural marketing, we found from our research that we needed to have people employed by us who were representative of the population we wanted to reach to get effective planning done.
- ➤ Zach Hall: We have currently 20 people and will be expanding mostly in the scientific area, but I hope in the long run we will be able to accomplish that. We only have 1 person doing communications right now.
- ➤ **Bob Klein:** In terms of the Board itself, there are four constitutional officers appointed to the ICOC. When appointments come up they look at people they know to replace those people, so you need to get suggestions in before the openings come up. They will default to the people in front of them when these opportunities come up unexpectedly.
- ➤ Participant #2: Going back to the definition of diversity, I'd like to start with the question of what are we trying to achieve. I think that it's the free flow and natural flow of research and the resulting therapies and information without regard to inappropriate barriers. It is a multifaceted and complex issue. I wonder if one of the things we should consider is to focus on what we do best and think about a grant to have a scientific approach to think about how we achieve this free flow at every level biologic materials, of patients in clinical trails, and of investigators that are brought on. At the end of the day this is what the CIRM stands for and a scientific approach will make it less likely we end up with an outcome that wasn't intended.
- ➤ Participant #10: I like this idea of diversity of workforce and suppliers. There needs to be information that allows the diversity in the state to reach out and participate in what will be a significant economic engine and making sure that doesn't happen with inside deals. We also need community outreach and I think good outreach into the communities is important, maybe by having a speakers' bureau. A program that looks in the area of career building will be interesting too. A study needs to take in enough of the variables.
- ➤ Zach Hall: We have been invited to speak to the Black Wall Street Merchants and Oakland's Rotary Club but a speakers' bureau that has members of the leadership of the communities has more power. We need a speakers' bureau of your leadership. You know how to reach those communities.
- **Participant #16:** Has there been any consumer research done in this area?
- **Bob Klein:** We did much surveying in this area during the campaign.

- **Participant #16:** Did you carve out different populations?
- **Bob Klein:** We did and the minority communities are great supporters of this research.
- ➤ Participant #10: It's a matter of education and trust. I think not only do you need speakers who are leaders in the community to be out there, but also people from your organization to help; that is also important. When the chairman comes into the community, that's important. That shows a lot of respect and gives the organization a chance to learn about the communities. It's an issue of education and trust.
- ➤ Participant #16: You already have an alliance. You can utilize some of those stakeholders and power brokers from the African American communities to support this. You have support for this area in concept. You need to continue and sustain this communication and get more minority speakers on board to make it a mainstay of the population.
- ➤ **Bob Klein:** The only way to maintain a high-level of support is to maintain our commitment and continue the efforts we made during the campaign. We were getting info in the media that they were most comfortable with and have the most validation.
- ➤ Participant #16: You always need to use the right vehicle. You are already ahead of the game if you have that support.
- ➤ **Bob Klein:** We have not had the staff in place to keep those gateways and communications open and we know the opposition will be persistent.
- ➤ Participant #19: Should we target specific disease? Wouldn't it be great if stem cell research could be used to help advance medicine and address the issues of minority disease? There is some kind of importance here. I think this is important, if we focus on disease, that there is a priority list to help us address stem cell research and diversity. Maybe we could list the top five issues.
- ➤ Participant #13: What's worked for us in terms of the diversity of suppliers is the idea of community reinvestment and holding these industries accountable to that. Just as an institute can encourage diversity among grantees and hold them accountable it can also create partnerships with industry. This also benefits them in terms of public relations. Looking at community reinvestments and trying to incorporate private industry would be a win-win situation. CIRM should look into that to encourage reinvestment.
- ➤ Participant #16: When we talk about organizations, we need to include faith based social and civil organizations, like the NAACP and the Urban League. You really need to tap as many organizations as possible. We who sit here are overwhelmed with other commitments and you can tap into many organizations for us. Also, in encouraging the support of communities you want to remind communities that because of us we were able to pass Proposition 71 through the legislature. Sometimes you need to remind people

how successful they were in the first place. When looking at groups to tap into you have your higher education institutions; SFSU is one of the most diverse campuses in the state.

- ➤ Participant #2: I want to reemphasize I have done a lot of clinical trials and when they are not going well I go in and ask questions. I have never asked why we are not getting enough Asian or African American subjects. We fix the general but not specific problems. CIRM could also have informal alliances with organizations like the Robert Wood Johnson Minority Scholar Association which have has a long history of giving out grants to minorities and supporting investigators of color.
- ➤ Participant #12: With respect to the question "What measures or milestones can CIRM use to gauge whether it is serving the diverse community of California?", I assume you mean metrics. You need very specific metrics to evaluate your effectiveness.
- ➤ Participant #1: With respect to the question "Should CIRM target specific diseases (including those that affect primarily a specific ethnic minority population or sex) or target research that has the greatest potential for broad applicability?" you can do both. There are organizations that are broad based but targeted towards specific populations. Good targets offer a start to developing support for a win that crosses all lines but is specific to specific ethnic groups.

3. What should CIRM's top priorities be?

- ➤ Participant #12: Community outreach and education. CIRM should take a proactive, not reactive stance, as you did with the campaign.
- ➤ Participant #17: Maybe we could have some sort of payback provision in this area from people receiving these grants just like the NIH has payback provisions. Maybe it could be that scientists are required to speak to the community about stem cells. The payback clause could be to participate in this outreach beyond the research you outlined in the grant. Students can participate as well.
- ➤ Participant #10: Diversity among workforce and suppliers because that will reach the community when they see an economic incentive to backing what it going on.
- ➤ Participant #9: Building the foundation of ethnic diversity for the next generation of scientists, clinicians, and technicians.
- ➤ Participant #1: The diversity and applicability of cell therapies because if they are not well understood in our communities we won't have the ability to incorporate diversity in our research. How we make sure that we are able to do it and what are our strategies? That includes outreach and communication. This needs to be highlighted a lot more in the communities. We need to understand how we will do it, which includes community outreach and education including for the political leadership. We have to be aware of what the threats are, if additional ban on research occur.
- **Participant #20:** The diversity of biological materials.

- ➤ **Participant #6:** Making sure our communities know what our organs, tissue, etc., will be used for.
- ➤ Participant #2: Using our grants to make sure we properly understand the relevant obstacles and therefore can use that information to make a strategy to overcome those obstacles.
- ➤ Participant #20: We talked a lot about diversity of clinical trials. How do we ensure that? We need to find out where the barriers are. I would suggest diversity in clinical trials is critical.
- ➤ Participant #2: We should be funding research to achieve diversity in clinical trials. You can use that same strategy for other issues and frame it as a grant-based scientific approach to understanding barriers to diversity.
- ➤ Participant #13: How funding would be prioritized and how that relates to different communities. Do we go after low hanging fruit or consider the needs of all Californians?
- ➤ Participant #16: Reminding us of what we mean by diversity a continuing commitment to it and an understanding of what it is.
- ➤ Participant #8: CIRM will need to go down different roads and some of these will uncover unexpected opportunities. We want to look at low hanging fruit because it's more readily achievable but also at things that have a broad impact like malaria and diabetes and hepatitis because there are so many people affected. If we target those we can go back to the communities.
- ➤ Participant #9: Identifying short term opportunities to address research that is relevant to minority populations but has broader applications. We should look for those opportunities and linkages.

CLOSING COMMENTS

> Zach Hall thanked all the attendees for participating, adding that he thought it had been a terrific discussion and hoped it was the beginning of an ongoing dialogue.

KEY TOPICS DISCUSSED

- Ensuring diversity / ethnic representation in clinical trials.
- Ensuring diversity and applicability of stem cell therapies.
- > Ensuring diversity of workforce and suppliers.
- Ensuring the diversity of biological materials.
- > Defining and considering different aspects of diversity.

- > Focusing on community outreach and education.
- > Creating a new model for funding research.
- > Building the next generation of scientists / clinicians.
- > Identifying short term opportunities that have broad applicability.